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## Development of the National Healthy Sleep Awareness Project Sleep Health Surveillance Questions

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**Objectives:** For the first time ever, as emphasized by inclusion in the Healthy People 2020 goals, sleep health is an emphasis of national health aims. The National Healthy Sleep Awareness Project (NHSAP) was tasked to propose questions for inclusion in the next Behavioral Risk Factor Surveillance System (BRFSS), a survey that includes a number of questions that target behaviors thought to impact health, as a means to measure community sleep health. The total number of questions could not exceed five, and had to include an assessment of the risk for obstructive sleep apnea (OSA).

**Methods:** An appointed workgroup met via teleconference and face-to-face venues to develop an inventory of published survey questions being used to identify sleep health, to develop a framework on which to analyze the strengths and weaknesses of current survey questions concerning sleep, and to develop recommendations for sleep health and disease surveillance questions going forward.

**Results:** The recommendation was to focus on certain existing BRFSS questions pertaining to sleep duration, quality, satisfaction, daytime alertness, and to add to these other BRFSS existing questions to make a modified STOP-BANG questionnaire (minus the N for neck circumference) to assess for risk of OSA.

**Conclusions:** Sleep health is an important dimension of health that has previously received less attention in national health surveys. We believe that 5 questions recommended for the upcoming BRFSS question banks will assist as important measures of sleep health, and may help to evaluate the effectiveness of interventions to improve sleep health in our nation.

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o promote optimal health and prevent illness, the US Department of Health and Human Services recommends that Americans "... Eat smart, exercise regularly, and get routine health screenings. Be an active participant in managing your health. Start leading a healthy lifestyle." While this advice includes quitting smoking, limiting alcohol, and cutting back on risky behaviors, it says nothing about sleep—most likely because national and state-level sleep surveillance data have not been as available as the other risk behaviors. However, there is growing appreciation for the importance of sleep in health maintenance and disease prevention. Healthy People 2020 added topics on sleep, including the intent to increase public knowledge of how adequate sleep and treatment of sleep disorders improve health, productivity, wellness, quality of life; it also includes topics on safety in the workplace and on the roads.<sup>2</sup> With the intention of facilitating the attainment of these goals, in 2013 the Centers for Disease Control and Prevention (CDC) partnered with two professional societies for sleep, the American Academy of Sleep Medicine and the Sleep Research Society, to create the National Healthy Sleep Awareness Project (NHSAP). Details of the project's activities can be found at http://www.sleepeducation.com/healthysleep/ about-the-national-healthy-sleep-awareness-project/.

One of the central missions of the NHSAP is to improve surveillance of sleep health in America, and as such, the NHSAP Surveillance and Epidemiology Workgroup, comprised of the authors, was formed and tasked to propose questions for inclusion in the next Behavioral Risk Factor Surveillance System (BRFSS), a survey that includes a number of questions that target behaviors thought to impact health.<sup>3</sup> The NHSAP chose to work to propose questions for inclusion in the BRFSS rather than another survey because it is conducted by telephone interview in all 50 states, District of Columbia, and the territories, and therefore achieves a demographically representative sampling of Americans. It is a very well-established, governmentsupported, annual surveillance tool, with a high standard of quality control of test questions, having been used in surveillance since 1984. The BRFSS has grown from approximately 100,000 telephone interviews in 1993, to over 500,000 per year at this time.

The BRFSS has included a sleep question since 1995, "During the past 30 days, for about how many days have you felt you did not get enough rest or sleep?," and sleep questions are in the list of "core" questions asked on alternating years. Since 2009, an optional sleep module has been included that asks, "On average, how many hours of sleep do you get in a 24-hour period?", "Do you snore?", "During the past 30 days, for about

Literature Search (PubMed, Google Scholar) **Pearl Growing** Identify Sleep-(search references of Review Strengths/ Related Questions Propose 5 Sleep lit search) Weaknesses of Health Surveillance from Prior Health Sleep Related Surveillance Questions Questions **Projects** Personal Referral (contact researchers

**Figure 1**—Overview of the sleep health surveillance question development process.

how many days did you find yourself unintentionally falling asleep during the day?"; "During the past 30 days, have you ever nodded off or fallen asleep, even just for a brief moment, while driving?"

named in lit search)

Examine CDC Inventories of Health Surveys

The BRFSS is conducted at state level to monitor prevalence of behaviors known or suspected to be associated with premature morbidity and mortality, and to characterize regional specific needs for targeted health awareness programs development and/or introduction. Further, once health risks are identified and interventions are developed and applied, the BRFSS can be used to evaluate the outcomes and the comparative effectiveness of interventional programs. For a new question to be included, a committee of professionals with expertise in the area of test development must screen the BRFSS question. Very few questions can be included each year because the BRFSS encompasses a large inventory of behaviors, space for questions is competitive, and they must be evidence-based. In addition, once sufficient evidence exists to warrant inclusion of a behavior for surveillance, it needs to be tested further and shown to be valid in order to maintain its inclusion.

The NHSAP Surveillance and Epidemiology Workgroup was specifically tasked to develop no more than five standardized survey questions that would assist in evaluating sleep health and risk for obstructive sleep apnea syndrome (OSA) for potential inclusion in the BRFSS. The rationale for and process by which questions were selected to propose to the BRFSS selection committee by the NHSAP is described below, followed by a description of next steps and future perspectives.

#### **DEVELOPMENT PROCESS**

The Workgroup met via teleconference monthly and via face-to-face meetings on three occasions. The work progressed in four stages: (A) perform a search for prior population health surveys that included sleep-related questions, (B) develop an

inventory of current instruments being used to identify sleep health and disease, (C) extract a list of prior sleep related questions from existing sleep health-related surveillance data, (D) determine a framework on which to analyze the strengths and weaknesses of current survey questions concerning sleep, and develop recommendations for sleep health and disease surveillance going forward (see Figure 1). Due to the required economies involved in national surveillance programs, the Workgroup was asked to identify no more than five questions to be used in the surveillance project. We jointly determined it would be desirable, where possible, to use established sleep health questions for two reasons: (a) data could be trended over longer periods of time by making use of prior survey data, and (b) time and money would be saved by avoiding the need to revalidate and address the question approval process for national surveys.

#### **Inventory of Current Instruments**

We began by identifying and evaluating current surveys and datasets with a sleep related component, including but not limited to those that have been previously administered by the CDC. We searched the medical literature using PubMed and Google Scholar, and conducted an updated review of the surveys reported in the National Heart, Lung, and Blood Institute (NHLBI) National Center on Sleep Disorders Research Guide to Selected Publicly Available Sleep-Related Data Resources.<sup>4</sup> A literature search for articles including sleep related surveillance data was conducted using the title of the survey (e.g., Behavioral Risk Factor Surveillance System) and the following keywords in the title or abstract of the publication: sleep, duration, satisfaction, quality, or apnea. The search was limited to studies that were done in humans and published in the English language. The databases were searched on September 5, 2014, with no starting publication date restrictions. In addition to the search, we

**Table 1**—National Healthy Sleep Awareness Project sleep health categories for tagging survey questions.

**Duration:** Addresses hours of sleep, either numerically or categorically

**Quality:** Addresses experience of sleep, difficulties getting to or staying asleep, interruptions of sleep, time awake in bed. In general should address issues that theoretically could be observed by a careful observer.

Satisfaction: Addresses restfulness or adequacy of sleep or sleep directly (question must address sleep as opposed to daytime function-see alertness), satisfaction with sleep, frustration with sleep quality. Really an internal subjective sense of sleep satisfaction.

**Alertness:** Addresses daytime function related to ability to stay alert, exhibit drowsiness, falling asleep inappropriately or in undesired situations, drowsy driving, etc.

**Obstructive Sleep Apnea Risk:** Addresses issues directly related to snoring, sleep-related apneas or choking or other symptoms of upper airway obstruction. Should include here questions about neck circumference, collar size, dimensions related to upper airway, BMI factors.

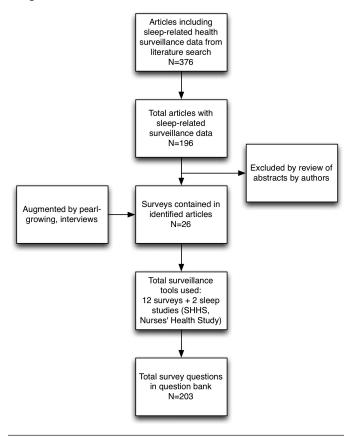
augmented our inventory by pearl growing (examining the articles referenced in those studies located by the formal literature search for relevance), by examining inventories of health surveys maintained by the CDC, and by interviewing personal sleep experts and public health contacts. Using the search results (Figure 1A), we compiled an inventory of surveys—and in particular, of the sleep related questions used in currently administered health surveillance surveys (Figure 1B). This yielded a large number of questions related in various ways to sleep duration, sleep quality, sleep satisfaction, symptoms of OSA, daytime sleepiness, daytime fatigue, etc. (Figures 1C and 2).

Our search yielded 376 publications that used health surveillance data containing sleep related questions. The following search results were found for each survey name coupled with the term sleep in the title/abstract: Behavioral Risk Factor Surveillance System (41 articles), Youth Risk Behavior Survey (12 articles), National Health Interview Survey (33 articles), National Health and Nutrition Examination Survey (67 articles), National Survey of Children's Health (10 articles), National Comorbidity Survey (16 articles), American Time Use Survey (5 articles), PatientsLikeMe Survey (1 article), Sleep In America Poll/National Sleep Foundation (21 articles), Pregnancy Risk Assessment Monitoring System (15 articles), National Survey of Early Childhood Health (2 articles), Nurses' Health Study (21 articles), General Social Survey (2 articles), Sleep Heart Health Study (130 articles). A further refined search coupled the survey name with the terms sleep duration, satisfaction, quality, or apnea which overlapped the original results. A complete list of returned references is provided in the supplemental material.

#### Framework for Analyzing Sleep Health

Although there have recently been at least two expert conferences convened to determine normative data for healthy sleep

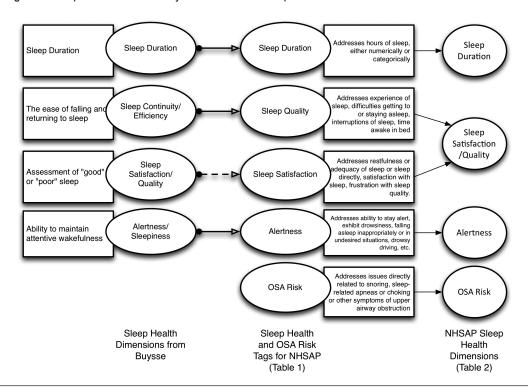
Figure 2—Review scheme and results of review.



duration, sleep duration is only one aspect of sleep health,<sup>5-7</sup> and there are currently no widely accepted constructs defining a more comprehensive way of assessing sleep health. In order to evaluate the usefulness of the sleep related questions found from our search as indicators for sleep health, we needed to come to consensus regarding the desirable elements of sleep health. We found the dimensions of sleep health described and justified by Buysse compelling: sleep duration, sleep continuity or efficiency, sleep timing, alertness/sleepiness, and sleep satisfaction/quality.8 Our question inventory from the search above was first qualitatively examined to look for similarities and differences between the existing question and these dimensions of sleep health. We found significant but incomplete overlap. For example, many existing survey questions attempt to ascertain a measure of sleep duration, although the actual questions vary. Alertness/sleepiness were assessed by some questions in surveys, but not using identical questions. In contrast, the concept of sleep satisfaction/quality described by Buysse as "the subjective assessment of 'good' or 'poor' sleep" was not directly asked in the existing question bank at all, though some questions alluded to the refreshing or the disrupted nature of sleep. Using this, we determined that we would use five general categories with which to tag the existing survey questions as we reviewed them: sleep duration, sleep quality, sleep satisfaction, alertness, and OSA risk (Table 1, Figure 3).

We specifically considered whether or not to include questions about segmented sleep or sleep timing, one of Buysse's

Figure 3—Moving from sleep dimensions of Buysse to NHSAP sleep health dimensions.



**Table 2**—National Healthy Sleep Awareness Project question recommendations.

Sleep Health Dimensions	Question (as adapted for NHSAP)
Duration (from NHIS)	On average, how many hours of sleep do you get in a 24-hour period? (Enter hours of sleep in whole numbers, rounding 30 minutes (1/2 hour) or more up to the next whole hour and dropping 29 or fewer minutes): number of hours (01–24), Don't know/Not sure, Refused
Satisfaction/Quality (BRFSS, PHQ-8)	Over the last 2 weeks, how many days have you had trouble falling asleep or staying asleep or sleeping too much? days (01–14), None, Don't know/not sure, Refused
Alertness (BRFSS 2009*)	During the past 2 weeks, for about how many days did you find yourself unintentionally falling asleep during the day? days (01–14), None, Don't know/not sure, Refused
OSA risk (STOP questionnaire adaptation**)	Snoring: During the past 2 weeks, for about how many days did you snore? days (01–14), None, Don't know/Not sure, Refused
	2. Tired (See Alertness above)
	3. Observed apneas: Has anyone observed you stop breathing during your sleep? Yes/No
	4. High Blood <b>P</b> ressure (note that the presence of hypertension or hypertension treatment is already a feature of current surveillance questionnaires)

<sup>\*</sup>With recommendation to change time frame from 30 days to 2 weeks. \*\*With recommendation to alter snoring question from loudness to frequency.

sleep health dimensions, in our development of survey questions. Existing questions pertaining to the sleep timing dimension would certainly be altered by whether or not the surveyed participant was involved in shift work or not, making comparison over time important but challenging. In addition, we needed to economize in order to remain within our allotment for five questions. Therefore, although circadian timing of sleep and its segmentation are very important, we decided to forego questions focusing on sleep timing for this iteration of question development.

#### **Analysis of the Question Bank**

The Workgroup members next constructed a data table, tagging questions in the question bank according to the NHSAP Sleep Health Categories (**Table 1**). For each question, we also noted the number of publications using that question, which population(s) was being addressed, and health outcomes that had been linked or evaluated in the context of those questions. Using these data, the Workgroup discussed the limitations and disadvantages of the current questions in view of our goal and the sleep health construct.

From this analysis, we decided to adapt questions from the National Health Interview Survey (NHIS) related to duration, from the BRFSS/Personal Health Questionnaire (PHQ-8) to form a combined dimension of sleep satisfaction/quality, and from the BRFSS to determine aspects of alertness (**Table 2**, **Figure 3**).

### The Special Problem of Assessing for the Risk of Obstructive Sleep Apnea

The clinical risk factors for and symptoms of obstructive sleep apnea syndrome are well described. However, none alone are sufficiently sensitive or specific to rightly assign a risk for OSA. Because of this, many clinical prediction rules have been developed to guide clinicians in their ability to stratify risk for OSA. For population surveys, we needed to depend upon selfanswered questions and to minimize the number of such questions used. Surveying for sleep duration, satisfaction/quality, and alertness consumed three of our five questions, leaving us room for two more questions in our survey question proposal. We agreed that using elements of the STOP questionnaire would be most advantageous (Table 2). Other questions in the BRFSS question bank already assess for hypertension (the "P" in STOP is for high blood pressure). Therefore, we reasoned that if our survey questions addressed Snoring, Tiredness, and Observed apneas, we could construct some inferences regarding the relative risk for OSA in survey respondents.

#### THE NHSAP SLEEP HEALTH QUESTIONS

Utilizing an informal consensus process and including the considerations above, we have selected the questions shown in **Table 2**. We arrived at these questions by following these principles:

- When possible, use existing questions from prior surveys. This reduces question development time and costs and allows comparison of answers across longer periods of time.
- Select questions that, as much as possible, correspond to a construct descriptive of sleep health across several dimensions, inclusive of sleep duration, timing, restorative quality, and satisfaction.
- 3. Select questions that will help stratify risk for OSA.
- 4. Select no more than 5 questions (a design parameter provided by the CDC).

The selected questions do satisfy these design features.

#### **LIMITATIONS**

This is a very ambitious project, and there are many potential limitations to our approach. First, without significant and validated prior measurement of sleep health across many dimensions, this must be considered an initial effort. Prior validated instruments which assess sleep quality (e.g., the Pittsburgh Sleep Quality Index, Calgary Sleep Apnea Quality of Life) require many more questions and are often disease-specific. There is no doubt that choosing and using only a limited number of questions will leave many questions about sleep health unanswered. There are also few data to determine if the particular dimensions of sleep quality chosen are most correlated with the biosocial consequences of "poor" sleep. Hopefully,

however, these questions, which address several dimensions of sleep, will serve to begin a more general understanding of sleep health in the United States.

The decision to reduce the amount of time from 30 days to two weeks in the sleep alertness question might be considered a limitation of the chosen approach, as it deviates from the historically used time frame included in the BRFSS for these questions. However, it was considered that it would be preferable to keep the time frame consistent across all questions. As the satisfaction question is based on two weeks, and recall is generally more accurate for this timeframe, the Workgroup chose to recommend using it consistently. Another item that was adopted but in a different form than previously used is the snoring item. Due to evidence presented by Caffo et al.<sup>9</sup> that showed that snoring frequency had more importance than snoring loudness in the prediction of respiratory disturbance index (RDI), the Workgroup decided to recommend the frequency item for inclusion.

Limitations of current surveillance surveys to assess sleep health include that the information obtained is retrospective and has potential for recall bias. Furthermore, the questions often assess sleep related complaints, which may be open to interpretation and could reflect a variety of underlying sleep disorders. Because large annual population surveys such as the NHIS and BRFSS are very expensive, time-limited, and do not allow a clinical examination, surveillance information on sleep health and sleep disorders is a subjective self-report and has no objective measurement for clinical validation. In population surveys such as the National Health and Nutrition Examination Survey (NHANES), which do include a physical examination, the use of either polysomnography or actigraphy is prohibitive in terms of cost, time limitations, and respondents' willingness to participate over more than one assessment day.

A major strength of current CDC surveillance surveys is that respondents represent the general population in contrast to participants selected according to specific inclusion-exclusion criteria in clinical studies. Therefore, the survey population is much more representative of the actual patient population that enters a physician's office with sleep complaints. An additional strength is the large sample sizes obtained for CDC surveillance surveys such as the NHIS, NHANES, BRFSS, and Youth Risk Behavior Survey (YRBS); this allows statistical power to assess disparities between groups defined by age, race/ethnicity, gender, educational attainment, income, and in some cases geography, that clinical studies cannot assess. Furthermore, each question represents a simple one-time measure of sleep disturbance that will permit analysis of secular trends.

## NEXT STEPS AND RECOMMENDATIONS FOR FURTHER DEVELOPMENT

These questions have been proposed and accepted for implementation in the BRFSS surveillance system. This is a formal process that involves presentation of the new questions for review by the BRFSS state coordinators. If selected for inclusion into a survey cycle, the questions then also undergo cognitive testing by an external group, and the process may also involve slight revisions of each question.

Selecting "good" questions that can be included in an existing survey without further evaluation increases the likelihood of their inclusion in the near future. "A good question is one that produces answers that are reliable and valid measures of something we want to describe." Questions must be asked and understood in a consistent manner, whether read by the respondents or read aloud by an interviewer. They should elicit the kind of answers that researchers want and expect. Questions should be ones that all respondents will have an answer to and are willing to answer. Evaluation studies are conducted to determine if the question captures the intended concept and is interpreted consistently over the range of demographic groups included in the survey.

A variety of quantitative and qualitative methods are used to ensure the questions produce valid answers with minimum measurement error. Cognitive interviewing is the primary method used by the Questionnaire Design Research Laboratory (QDRL) of the CDC and other government agencies. Cognitive interviewing involves conducting interviews of several selected sample groups of up to approximately 50 respondents, summarizing and comparing across respondents, across groups, and then formulating conclusions about question performance. Inclusion in surveys such as the BRFSS requires that questions have been developed and evaluated according to current accepted methodology.

If selected as an optional module by the BRFSS state coordinators, then an individual state health department determines whether that state's BRFSS will add the sleep health module to their annual survey. Interest in the addition of this module could often be determined by whether the information obtained in the module will provide additional guidance for state chronic disease programs or will enhance or add value to ongoing prevention and intervention programs being implemented by organizations such as the state sleep society. Continued implementation of the sleep health module in further survey years will also be determined by the analysis, interpretation, and use of the information.

Researchers in the sleep field are encouraged to make use of the BRFSS and other CDC surveillance data and to query and publish results of analyses of sleep health and risk for morbidity and mortality in many health domains. The use of the data will ensure that this information continues to be collected and that findings get attention and consideration by decision makers and stakeholders working to improve the health and wellness of the nation.

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#### **SUBMISSION & CORRESPONDENCE INFORMATION**

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